



# I believe I can fly

The power of patient experience

Report on the engagement and involvement event for people who use the Nottingham Sickle Cell and Thalassaemia Service - Hilton Hotel, 21st July 2009

## I believe I can fly: The POWER of patient experience

The Nottingham Sickle Cell and Thalassaemia Service recognises the value of engaging people who use the service to plan service improvements. The Service commissioned Bright Ideas Nottingham, an independent organisation, to plan and host an event with the following aims:

to celebrate the achievements of the Sickle Cell and Thalassaemia Service

to provide recommendations for developing and improving the service

to provide a motivational and inspirational event for the client group.

The event was held at the Hilton Hotel. It was important that the event was held in a warm and comfortable venue and somewhere that acknowledged the importance of the issues to be discussed. The event's programme proved attractive, and individuals and families gave up their time to engage with the Sickle Cell and Thalassaemia Service. This report provides a summary of the event and feedback from participants.



*Pete Campbell sang; we danced*

# I believe I can fly: Introduction

Pete Campbell warmed up the audience with some reggae, and the very lively, charismatic compere, BBC presenter Trish Adudu, started by welcoming the 75 event participants and by explaining the aims and objectives of the day.

*Compere, BBC's Trish Adudu, photographed here with special guest Des Walker*



## I can fly: Sharing our positive experiences

The guest speaker Ajay gave a powerful and moving speech about his own experiences of living with both sickle beta thalassaemia.

Ajay lives in Birmingham and has developed a successful career in working with and supporting young people to realise their ambitions. Many people in the audience were able to relate to both the experiences and the associated feelings that Ajay shared. The impact that his diagnosis had on himself, his family and his friends was shared with the audience in a factual, sometimes humorous but nonetheless touching way. Ajay talked about the journey of trying to find the right treatment for him – the trials when things did not go so well and the ultimate relief of having treatment that was able to make a real difference to the quality of his life. The clear message was that living with a long-term condition can have extremely challenging consequences, physically, emotionally and psychologically. However, ambitions can be achieved when individuals recognise the contributions they can make and work with services to treat and manage the condition effectively. The support and understanding from other people could not be over-emphasised, and are one of the reasons why



*Guest speaker Ajay: an inspiring and moving personal story*

Ajay is committed to sharing his experiences with others. It was an inspiring speech, befitting an event that proved to be an uplifting and encouraging occasion for all involved. Several participants took the microphone to tell their equally motivational stories, acknowledging the pain – both physical and emotional – of living with the condition as well as the triumphs and successes. Faith in a higher power was a theme that was repeated throughout this session. Spirituality was essential to people's coping mechanisms and their ability to face the future in a positive way.